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Original article

Is a National Registry for Congenital Cranial Deformities Needed? Insights from a Single-Center Analysis of 96 Cases

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Abstract

The aim of this research is to describe the clinical and regional epidemiological characteristics of craniosynostosis in Kazakhstan based on a single-center surgical cohort and to emphasize the need for national registry implementation and integrated data collection. This retrospective study included 96 pediatric patients who underwent surgery for craniosynostosis at the National Centre for Neurosurgery (Astana) between April 2021 and August 2023. Data on clinical subtype, sex distribution, age at surgery, and regional origin were analyzed. Diagnoses were confirmed by neuroimaging (computerized tomography scan, magnetic resonance imaging, cranial ultrasound). Exclusion criteria included secondary craniosynostosis, incomplete records, or revision surgeries. Sagittal craniosynostosis was the most frequent subtype (58.3%), followed by coronal (22.9%), metopic (9.4%), and lambdoid (2.1%). Multisuture fusion was exclusively represented by bicoronal synostosis (8.3%). A clear male predominance (64.6%) was observed, particularly in sagittal cases. Most patients (68.8%) were treated within the first year of life. Regional analysis revealed marked disparities, with Southern Kazakhstan contributing the largest share of cases (39.6%) and several regions underrepresented or absent. Annual case numbers remained relatively stable between 2021 and 2023. This study provides the first structured insight into the clinical epidemiology of craniosynostosis in Kazakhstan, highlighting diagnostic delays, regional disparities, and the absence of a unified data system. The findings underscore the urgent need for a national congenital anomaly registry, standardized screening protocols, and expanded access to diagnostic and surgical care. These measures are essential for equitable, timely, and effective management of craniosynostosis in Kazakhstan.

Keywords: craniosynostosis, epidemiology, Kazakhstan, congenital anomaly, pediatric neurosurgery, registry, diagnostic access.

1. Introduction

Craniosynostosis is a congenital cranial deformity caused by the premature fusion of one or more cranial sutures, which impedes normal skull growth in the direction perpendicular to the affected suture. This

results in an abnormal cranial morphology and, in certain cases, increased intracranial pressure and associated neurological impairments [1, 2].

Two primary clinical categories are recognized: syndromic craniosynostosis, which is associated with other congenital anomalies, and nonsyndromic craniosynostosis, characterized by isolated suture fusion without additional systemic malformations. Nonsyndromic cases account for approximately 75-85% of all craniosynostosis diagnoses [3]. The most commonly encountered forms include sagittal (scaphocephaly), metopic (trigonocephaly), coronal (plagiocephaly), and lambdoid types [4]. Sagittal craniosynostosis is the most prevalent, particularly among male patients, whereas coronal craniosynostosis is more frequently observed in females [5].

Epidemiological data from Europe, the United States, and Australia report an incidence ranging from 3 to 7 per 10,000 live births, with a rising trend notably observed in metopic craniosynostosis [4, 6-7]. This increase is attributed to several factors, including advanced parental age, the use of assisted reproductive technologies such as *in vitro* fertilization (IVF), improved diagnostic capabilities, and heightened awareness among healthcare professionals [8].

Despite the availability of comprehensive clinical and epidemiological data in international literature, no population-based studies have been conducted in Kazakhstan to assess the true incidence or clinical course of craniosynostosis. The absence of a national registry for congenital malformations may partly explain the delayed diagnosis of craniosynostosis in children, which in turn complicates timely and optimal surgical planning. This concern has been echoed by previous researchers [6, 9]. A systematic investigation of the clinical and epidemiological characteristics of craniosynostosis in Kazakhstan is essential for the development of screening programs, national diagnostic and treatment standards, and prognostic models. These efforts would contribute to the early identification of affected individuals, enhance the quality of specialized care, and ultimately reduce disability rates among children with craniosynostosis.

The aim of this research is to describe the clinical and regional epidemiological characteristics of craniosynostosis in Kazakhstan based on a single-center surgical cohort and to emphasize the need for national registry implementation and integrated data collection.

2. Materials and methods

The present study is a retrospective, single-center clinical observation conducted in the Department of Pediatric Neurosurgery at the National Centre for Neurosurgery (Astana, Kazakhstan) between April 2021 and August 2023. The primary objective of this investigation was to analyze the clinical epidemiological characteristics of craniosynostosis in the Republic of Kazakhstan, with a specific focus on sex distribution, regional variation in prevalence, and the relative frequency of different clinical forms of craniosynostosis.

Inclusion criteria

The study enrolled pediatric patients with a confirmed diagnosis of craniosynostosis who were admitted and surgically treated at the National Centre for Neurosurgery between April 2021 and August 2023. At the time of surgery, the patients were no older than 8 years, reflecting the upper age limit of the studied cohort. The diagnosis of craniosynostosis - both syndromic and nonsyndromic forms - was established based on clinical examination and neuroimaging findings, including computed tomography (CT), magnetic resonance imaging (MRI), and cranial ultrasonography. All consecutive patients who met the inclusion criteria and underwent surgical treatment during the study period were enrolled in the study. No formal sample size calculation was performed, as all available eligible cases within the study period were included in the analysis.

Exclusion criteria

Patients with secondary craniosynostosis associated with metabolic, neurosurgical, or post-traumatic etiologies were excluded. Additional exclusion criteria included the presence of severe somatic or genetic comorbidities that contraindicated surgical intervention, incomplete medical records, lack of neuroimaging data, parental refusal to participate in the study, or cases involving revision surgeries or secondary cranial procedures. The latter were excluded to prevent duplication of data and potential selection bias.

A total of 96 patients were included in the final analysis, comprising 62 males and 34 females. Patients were classified by age group (≤12 months, 1-5 years, and ≥5 years), geographical region within the Republic of Kazakhstan, sex, and type of craniosynostosis. The classification was performed to assess potential associations between demographic, regional, and

clinical factors and the types of craniosynostosis observed within the cohort. Regional attribution was based on the official place of permanent residence (registration address) of each patient, as documented in the medical records at the time of admission.

Statistical Analysis

Descriptive statistics were used to summarize patient demographics and clinical characteristics, including frequencies and percentages for categorical variables.

Associations between categorical variables - specifically, craniosynostosis type, sex, age group, and geographical region - were assessed using the Chi-square test of independence. For contingency tables with expected cell counts <5, Fisher's exact test with Monte Carlo simulation was applied. The strength of associations was estimated using Cramér's V coefficient. A p-value <0.05 was considered statistically significant. All analyses were performed using Jamovi software (version 2.6.44.0; The Jamovi Project, Sydney, Australia).

3. Results

General characteristics of the cohort

The study cohort comprised 96 patients diagnosed with craniosynostosis who underwent surgical intervention before the age of 8 years. The majority of patients (n = 48; 50.0%) underwent surgery during the first year of life, reflecting the established early referral pathways. The group aged between 1 and 5 years included 46 patients (47.9%), while only 2 patients (2.1%) were older than 5 years at the time of surgery. The distribution of craniosynostosis types across age groups is summarized in Table 1.

Table 1 – Distribution of craniosynostosis types by age groups (n = 96)

Diagnosis	≤ 12 months	1–5 years	≥ 5 years	Total
Sagittal craniosynostosis	26 (27.1%)	28 (29.2%)	2 (2.1%)	56
Bicoronal craniosynostosis	4 (4.2%)	4 (4.2%)	0 (0.0%)	8
Syndromic craniosynostosis	5 (5.2%)	2 (2.1%)	0 (0.0%)	7
Metopic craniosynostosis	8 (8.3%)	1 (1.0%)	0 (0.0%)	9
Unilateral coronal craniosynostosis	5 (5.2%)	9 (9.4%)	0 (0.0%)	14
Unilateral lambdoid craniosynostosis	0 (0.0%)	2 (2.1%)	0 (0.0%)	2
Total	**48 (50.0%)**	**46 (47.9%)**	**2 (2.1%)**	**96**

No statistically significant association was found between age groups and craniosynostosis type (χ^2 (10) = 11.6, p >0.05). Fisher's exact test confirmed this result (p > 0.05).

Types of craniosynostosis

Among all included patients (n=96), nonsyndromic craniosynostosis was diagnosed in the vast majority - 89 patients (92.7%), whereas syndromic forms were identified in 7 patients (7.3%). In most cases (91.7%), craniosynostosis involved the isolated fusion of a single cranial suture. Descriptive statistics were applied to summarize the distribution of craniosynostosis types within the study cohort (Table 1).

Multisuture craniosynostosis was less common, observed in only 8 patients (8.3%), all of whom presented with bicoronal synostosis. This subgroup included 6 female and 2 male patients. No other combinations of fused sutures were identified in this cohort.

Regarding suture-specific distribution, sagittal craniosynostosis was the most prevalent form, diagnosed in 56 patients (58.3%). Coronal craniosynostosis - including both unilateral and bilateral cases - was identified in 22 patients (22.9%), of whom 8 (8.3%) had bilateral involvement. As showed in Table 1 the metopic type (trigonocephaly) was recorded in 9 patients (9.4%), while lambdoid craniosynostosis was the least frequent, found in only 2 patients (2.1%).

Sex-based distribution

Among the 96 patients included in the study, 62 (64.6%) were male and 34 (35.4%) were female. A

significant association was observed between craniosynostosis type and patient sex ($\chi^2 = 13.1$; df = 5; p = 0.023; Fisher's exact test p = 0.021). The strength of this association, as measured by Cramér's V, was moderate (V = 0.369).

Sagittal craniosynostosis was predominantly diagnosed in male patients (n = 41; 73.2%), with only 15 cases (26.8%) identified in females. Conversely, bicoronal craniosynostosis showed a marked female predominance (n = 6; 75.0%), with just 2 male cases (25.0%). Syndromic forms were slightly more frequent in males (n = 5; 71.4%) than females (n = 2; 28.6%).

Similarly, metopic craniosynostosis was more common among male patients (n = 7; 77.8%), while unilateral coronal craniosynostosis demonstrated an equal distribution between sexes (n = 7; 50.0% each). Notably, both identified cases of unilateral lambdoid craniosynostosis occurred in female patients (100%). These findings suggest potential sex-related differences in the distribution of craniosynostosis types within the study cohort. (Table 2).

Table 2 – Distribution of Craniosynostosis Types by Sex (n = 96)

Diagnosis	Female, n (%)	Male, n (%)	Total, n (%)
Sagittal craniosynostosis	15 (26.8)	41 (73.2)	56 (58.3)
Bicoronal craniosynostosis	6 (75.0)	2 (25.0)	8 (8.3)
Syndromic craniosynostosis	2 (28.6)	5 (71.4)	7 (7.3)
Metopic craniosynostosis	2 (22.2)	7 (77.8)	9 (9.4)
Unilateral coronal craniosynostosis	7 (50.0)	7 (50.0)	14 (14.6)
Unilateral lambdoid craniosynostosis	2 (100.0)	0 (0.0)	2 (2.1)
Total	**34 (35.4)**	**62 (64.6)**	**96 (100.0)**

A significant association was observed between craniosynostosis type and patient sex ($\chi^2 = 13.1$; df = 5; p = 0.023; Fisher's exact test p = 0.021). The strength of this association was moderate (Cramér's V = 0.369).

Regional distribution

Patients were grouped into five major geographical regions of Kazakhstan. The largest proportion of cases was recorded in Southern Kazakhstan (n = 38; 39.6%), followed by Western Kazakhstan (n = 24; 25.0%), Central Kazakhstan (n = 22; 22.9%), Northern Kazakhstan (n = 7; 7.3%), and Eastern Kazakhstan (n = 5; 5.2%).

Table 3 – Distribution of Craniosynostosis Types by Geographical Region (n = 96)

Diagnosis	Southern Kazakhstan	Eastern Kazakhstan	Northern Kazakhstan	Central Kazakhstan	Western Kazakhstan	Total
Sagittal craniosynostosis	20	0	5	13	18	56
Bicoronal craniosynostosis	1	2	0	2	3	8
Syndromic craniosynostosis	1	0	2	3	1	7
Metopic craniosynostosis	6	2	0	1	0	9
Unilateral coronal craniosynostosis	10	0	0	3	1	14
Unilateral lambdoid craniosynostosis	0	1	0	0	1	2
Total	**38**	**5**	**7**	**22**	**24**	**96**

Sagittal craniosynostosis was the most prevalent type across all regions, especially in Southern (n=20) and Western Kazakhstan (n=18). Unilateral coronal craniosynostosis was predominantly observed in

Southern Kazakhstan (n=10), while metopic craniosynostosis cases were mainly concentrated in Southern (n = 6) and Northern Kazakhstan (n = 2).

Bicoronal craniosynostosis and syndromic forms showed a scattered distribution with no clear regional dominance.

A statistically significant association was found between the geographical region and craniosynostosis type (χ^2 = 47.3; df = 20; p < 0.001; Fisher's exact test p = 0.002), indicating regional variability in the distribution of craniosynostosis subtypes (Table 3).

4. Discussion

This study represents a pilot attempt to characterize the epidemiological features of craniosynostosis in Kazakhstan in the lack of centralized national surveillance for congenital anomalies. Based on a single-center cohort of surgically treated patients at the National Centre for Neurosurgery in Astana, the findings offer a partial but valuable snapshot of the clinical and geographical distribution of craniosynostosis within the country.

Among the 96 patients included in the final analysis, sagittal craniosynostosis was the most frequently diagnosed subtype, accounting for 58.3% of cases. Coronal craniosynostosis - including both unilateral and bicoronal forms – represented 22.9%, while metopic and lambdoid forms were observed in 9.4% and 2.1% of patients, respectively. These figures are in line with international reports, where sagittal craniosynostosis accounts for approximately 40-55% of nonsyndromic cases [5, 7, 10, 11]. The higher proportion of sagittal cases in our cohort may reflect the predominance of severe cranial deformities, which prompts earlier referral, particularly in regions with limited access to specialized care.

Our data revealed a distinct male predominance (64.6%), corresponding to a male-to-female ratio of 1.72:1. This aligns with global trends indicating increased male susceptibility to sagittal and metopic synostoses [11-13]. In our cohort, sagittal craniosynostosis was diagnosed in 41 males (73.2%) and only 15 females (26.8%), a statistically significant association (χ^2=13.1; df = 5; p <0.05). This sexual dimorphism is believed to be influenced by androgenic effects on cranial suture biology during early development, supporting the multifactorial etiology of craniosynostosis involving genetic, hormonal, and possibly environmental factors [14-16]. Whether population-specific genetic or environmental factors influence these sex-based differences in craniosynostosis prevalence remains unknown and warrants further investigation.

Although our study does not provide a population-based incidence, the subtype distribution corresponds with global reports from Europe, North America, and Asia, where the prevalence ranges between 3 and 7 per 10,000 live births [17-19]. For example, studies from Finland report an incidence of 6.0 per 10,000, Norway 5.5 per 10,000, and Korea approximately 3.5 to 4.5 per 10,000 [17-20]. Unlike in North America and Australia - where an increasing trend in metopic craniosynostosis has been observed over recent decades - no temporal trend analyses have yet been conducted in Kazakhstan [21]. Nevertheless, our dataset showed a relatively stable annual number of surgical cases over the three years from 2021 to 2023, with minor fluctuations (Figure 1).

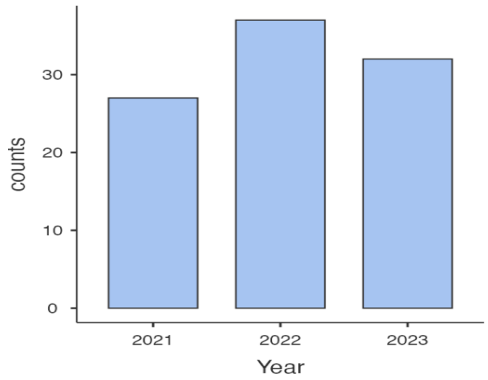

Figure 1 – Annual distribution of craniosynostosis surgeries performed at the National Centre for Neurosurgery between 2021 and 2023

While this observation does not allow for formal trend analysis, it highlights the necessity of continuous multicenter data collection to detect potential epidemiological shifts in the future.

The regional analysis of patient origins, grouped by macroregions, revealed notable geographical disparities. The highest proportion of cases originated from Southern Kazakhstan (38 cases; 39.6%), followed by Western Kazakhstan (24 cases; 25.0%) and Central Kazakhstan (22 cases; 22.9%). Fewer cases were recorded from Northern Kazakhstan (7 cases; 7.3%) and Eastern Kazakhstan (5 cases; 5.2%). The absence or low number of patients from specific regions within these macrozones likely reflects a combination of factors, including disparities in diagnostic capabilities, inconsistencies in referral pathways, the activity of independent surgical centers not included in this study, and varying levels of patient awareness. Additionally, some patients may have sought treatment abroad, contributing to underrepresentation in the dataset.

A statistically significant association between craniosynostosis type and geographical region was confirmed (χ^2=47.3; df = 20; p<0.001), indicating regional variability in subtype distribution. However, this result should be interpreted with caution given potential referral biases and the single-center design of the study. The current data emphasize the need for nationwide coordination of diagnostic and surgical services, as well as the establishment of a centralized registry for congenital anomalies. The implementation of ICD-10 coding (Q75.0) could facilitate the extraction of cases from existing health records, but without standardized data collection and clinical verification, such analyses remain limited in their epidemiological value.

This study has several important limitations. First, its single-center retrospective design, based on data from a tertiary care center in Astana, may introduce referral bias and limit the generalizability of the findings to the broader population of Kazakhstan. The absence of patients from certain regions likely reflects disparities in healthcare access, variations in diagnostic capabilities, inconsistent referral practices, and the activity of independent surgical centers not included in this analysis. Moreover, some patients may have received treatment abroad, further contributing to incomplete national case capture.

Additionally, only first-time surgical cases were included to avoid data duplication, which may underestimate the overall clinical burden of craniosynostosis. Despite regional attribution being based on the patients' official place of residence, variability in diagnostic criteria and referral pathways could have influenced the observed distribution. The lack of universally implemented prenatal and postnatal screening programs likely delays the diagnosis of milder or syndromic cases, further contributing to underdiagnosis. However, the annual distribution of surgical cases from 2021 to 2023 in our cohort appeared relatively stable, without a clear increasing or decreasing pattern. This underscores the importance of future multicenter studies with broader temporal coverage to assess possible epidemiological trends. Additionally, the study did not account for regional birth rates or population size, which limits the ability to calculate prevalence rates and accurately compare disease burden across regions. Finally, no formal genetic or molecular testing was conducted, which restricted the ability to establish genotype–phenotype correlations in suspected syndromic cases.

The limited availability of prenatal and postnatal screening programs in Kazakhstan may also contribute to delayed diagnoses, particularly in remote or underserved areas. While recent advances in perinatal care and improved awareness among pediatric specialists have enhanced early detection rates, these efforts remain insufficient to alter the national epidemiological profile significantly. Late diagnosis may lead to suboptimal timing of surgical intervention, potentially affecting neurodevelopmental outcomes. These findings highlight the necessity for establishing a multicenter, prospective registry that would enable comprehensive epidemiological surveillance of craniosynostosis across Kazakhstan. Such a registry would facilitate the development of evidence-based screening programs, standardized treatment protocols, and equitable access to specialized surgical care.

Addressing these challenges requires a nationwide strategy that emphasizes prenatal screening, streamlined diagnostic services, the implementation of a national congenital anomalies registry, and the development of coordinated care pathways.

5. Conclusions

This study offers a first systematic characterization of the clinical and regional epidemiology of craniosynostosis in Kazakhstan, based on a single-center surgical cohort. While the observed subtype

distribution, male predominance, and regional disparities align with international trends, they also highlight specific challenges within the Kazakhstani healthcare system - particularly concerning access to early diagnosis, specialized care, and coordinated referral pathways.

Given the single-center retrospective design, the findings should be interpreted with caution, as they may not fully capture the nationwide epidemiological landscape. Nevertheless, the results underscore the pressing need for establishing a multicenter, prospective registry to enable comprehensive surveillance of craniosynostosis across Kazakhstan. Such a registry would facilitate data integration, inform health policy planning, and support the development of standardized diagnostic and treatment protocols; consequently, further multicenter studies are warranted to validate these findings on a national level.

Effectively addressing these challenges will require a coordinated national strategy that includes the implementation of prenatal and postnatal screening programs, expansion of diagnostic and surgical services, creation of multidisciplinary care pathways, and development of a centralized congenital anomaly registry. These measures are critical to ensuring equitable access to care, timely diagnosis, and improved long-term neurodevelopmental outcomes for children affected by craniosynostosis in Kazakhstan.

Conflict of interest. Authors declare no conflicts of interest.

Financing. None.

Ethical approval. The study was conducted following the Declaration of Helsinki and the principles of Good Clinical Practice. Written informed consent was obtained from the legal guardians for inclusion in the study and data analysis. The project underwent ethical review and was approved by the local Ethics Committee of the National Centre of Neurosurgery, Astana, Kazakhstan, thereby safeguarding the participants' rights and safety.

Author contributions: Conceptualization – S.B.S.; Methodology – S.B.S.; Formal analysis – D.K.Z., S.B.S.; Data collection and analysis – S.B.S., Kh.A.M.; Statistical analysis – D.K.Z.; Drafting of the manuscript – D.K.Z.; Review and editing – G.I.O., Kh.A.M.; Preparation of figures and tables – Kh.A.M.; Final approval of the manuscript – S.B.S.

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Туа біткен бас сүйек деформациялары бойынша ұлттық тіркеу қажет пе? Бір орталықта жүргізілген 96 жағдайды талдау негізіндегі клиникалық қорытындылар

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Түйіндеме

Зерттеудің мақсаты: Қазақстандағы бір орталықтың хирургиялық деректеріне сүйене отырып, краниосиностоздың клиникалық және аймақтық эпидемиологиялық сипаттамаларын сипаттау, сондай-ақ ұлттық тіркелім мен біріктірілген деректерді жинау қажеттігін көрсету. Бұл ретроспективті зерттеуге 2021 жылдың сәуірі мен 2023 жылдың тамызы аралығында Астана қаласындағы Ұлттық нейрохирургия орталығында

краниосиностоз диагнозымен ота жасалған 96 педиатриялық науқас енгізілді. Клиникалық ерекшеліктері, жыныстық ара қатынасы, ота жасалған жасы және науқастың тұрғылықты жері (өңірі) бойынша деректер талданды. Диагноз нейровизуализация әдістері (компьютерлік томография, магнитно-резонанстық томография, бас сүйегін ультрадыбыстық зерттеу) арқылы расталды. Екінші реттік краниосиностоз, толық емес деректер немесе қайта жасалған оталар зерттеу құрамына кірмеді. Ең жиі кездесетін түрі - сагиттальді краниосиностоз (58,3%), кейін коронарлық (22,9%), метопиялық (9,4%) және ламбдовидті (2,1%) түрлері тіркелген. Көптік тігістердің бітісуі тек бикоронарлық синостоз түрінде байқалды (8,3%). Ер балалардың басымдығы тіркелді (64,6%), бұл әсіресе сагитталды формада көрініс тапты. Науқастардың басым көпшілігіне (68,8%) өмірінің алғашқы жылының ішінде ота жасалды. Аймақтық талдау айқын теңсіздіктерді көрсетті: жағдайлардың ең көп үлесі Оңтүстік Қазақстанға (39,6%) тиесілі, ал кейбір өңірлер мүлде тіркелмеген. Жыл сайынғы жағдайлардың саны 2021–2023 жылдары салыстырмалы түрде тұрақты деңгейде қалды. Бұл зерттеу Қазақстандағы краниосиностоздың клиникалық эпидемиологиясына алғашқы құрылымдық талдау ұсынып отыр. Диагностикадағы кідірістер, өңіраралық теңсіздіктер және бірыңғай деректер жүйесінің болмауы айқындалды. Авторлар туа біткен аномалиялар бойынша ұлттық тіркеу жүйесін құрудың, стандартталған скринингтік хаттамаларды енгізудің, сондай-ақ, диагностика мен хирургиялық көмектің қолжетімділігін кеңейтудің маңыздылығын атап өтеді. Аталмыш шаралар краниосиностозбен ауыратын балаларға дер кезінде, тиімді және тең қолжетімді медициналық көмек көрсету үшін аса маңызды.

Түйін сөздер: краниосиностоз, эпидемиология, Қазақстан, туа біткен аномалия, балалар нейрохирургиясы, тіркелім, диагностикалық қолжетімділік.

Необходим ли национальный регистр врожденных черепных деформаций? Клинические выводы из одноцентрового анализа 96 случаев

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Резюме

Цель исследования: описать клинические и региональные эпидемиологические характеристики краниосиностоза в Казахстане на основе данных хирургического наблюдения одного центра, а также обосновать необходимость создания национального регистра и интегрированного сбора данных. В это ретроспективное исследование включены 96 детей, перенесших хирургическое лечение краниосиностоза, прошедших лечение в Национальном центре нейрохирургии (Астана) в период с апреля 2021 по август 2023 года. Были проанализированы данные по клиническим подтипам, половому распределению, возрасту при проведении операции и региону пациентов. Диагноз подтверждался методами нейровизуализации (компьютерная томография, магнитно-резонансная томография, ультразвуковое исследование черепа). Исключались случаи вторичного краниосиностоза, неполные записи и повторные операции. Наиболее частой формой был сагиттальный краниосиностоз (58,3%), за ним следовали коронарный (22,9%), метопический (9,4%) и ламбдовидный (2,1%) типы. Множественное сращение швов представлено исключительно бикоронарным синостозом (8,3%). Отмечено преобладание мальчиков (64,6%), особенно при сагиттальной форме. Большинство пациентов (68,8%) были прооперированы в течение первого года жизни. Региональный анализ выявил выраженные диспропорции: наибольшее количество случаев зарегистрировано в Южном Казахстане (39,6%), в то время как некоторые регионы были представлены слабо или отсутствовали. Ежегодное количество случаев оставалось относительно стабильным в 2021–2023 годах. Данное исследование представляет собой первое структурированное описание клинической эпидемиологии краниосиностоза в Казахстане, выявляя задержки в диагностике, региональные дисбалансы и отсутствие единой системы данных. Полученные результаты подчеркивают срочную необходимость создания национального регистра врожденных аномалий, внедрения стандартных скрининговых протоколов и расширения доступа к диагностике и хирургической помощи. Эти меры необходимы для обеспечения своевременного, эффективного и справедливого лечения краниосиностоза в Казахстане.

Ключевые слова: краниосиностоз, эпидемиология, Казахстан, врожденная аномалия, детская нейрохирургия, регистр, диагностическая доступность.